HOW CAN WE HELP?

A new look at self-determination, interdependence, substitute decision making and guardianship in B.C.

A PAPER

INVITING PUBLIC AND GOVERNMENT DISCUSSION AND COMMENT

MAY 1992

Prepared by the Joint Working Committee, with equal representation from government (Interministry Committee on Issues Affecting Dependent Adults) and community (the Project to Review Adult Guardianship)

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This document reflects the work and commitment of three thousand people province-wide. Our thanks to each and every person for their involvement. We look forward to your comments on this discussion paper.

Our thanks to the Mental Health Coordination Project, B.C. Health Association for formatting this discussion paper in preparation for its printing and distribution.

NOTE TO READERS

This discussion paper reflects a synthesis of considerable dialogue, commentary and analysis, but it is not the final word.

Specific questions are raised throughout the text and we hope that readers who wish to comment on these — or on the entire discussion paper — will respond by contacting the Joint Working Committee before August 31, 1992.

We welcome and encourage all of your ideas, comments and suggestions. We also encourage you to photocopy this discussion paper and distribute it widely.

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INTRODUCTION

BACKGROUND

In 1989, a number of community organizations and interested individuals from all walks of life came together to establish the Project to Review Adult Guardianship as a community-based forum for discussing their concerns about current adult guardianship legislation, procedures and policies.

After more than a year of discussion and debate, both within the community and with the government's Interministry Committee on Issues Affecting Dependent Adults, the Project to Review Adult Guardianship published its initial Framework Document in the summer of 1991.

Shortly after that, members of the community-based Project and the Interministry Committee joined together to create a Joint Working Committee to continue discussion and debate, and review and refine the Framework Document.

THIS DISCUSSION PAPER

This discussion paper builds on the work of the Project to Review Adult Guardianship's Framework Document.

To produce this paper, the Joint Working Committee weighed and considered all verbal and written responses to the Framework Document received over an eight month consultation period. In addition, the Committee integrated the Project's existing task groups to wrestle with the complexities of specific areas of concern, such as consent to health care and expanding the existing grant of enduring Power of Attorney.

Although the Joint Working Committee now believes that it has created a paper that represents and balances the concerns, interests and objectives of all interested parties, some questions still remain unanswered. We invite comment and response on these questions — and on all the proposals presented here — from any interested person or organization.

Ultimately, after more consultation and refinement where necessary, the Committee hopes that this discussion paper will form the basis of new adult guardianship legislation, procedures and policies. However, no decision has been made as yet on the form in which the various proposals outlined here should be presented to the legislature: a single, omnibus statute is probably neither feasible nor desirable; a large number of separate statutes is equally unacceptable.

At this point, the Committee can only guarantee that the most economical and effective legislative package will be presented, and that the legislation will be written in plain language.

FOCUS

The focus of this discussion paper is the reform of legislation, procedures and systems affecting the support, assistance and protection of British Columbians who find it difficult to care for themselves, their property or their financial affairs.

Those affected by this legislation and the proposals outlined here include:

- adults with a mental handicap, mental illness, severe physical disability or head injury;
- adults who have experienced a stroke or have a degenerative disease or illness such as Alzheimer Disease, Huntington Disease or AIDS; and
- all citizens of this province who may in future experience diminishing capacity.

Throughout this document we will refer to a person affected by this legislation as the "adult".

RATIONALE

The reforms proposed in this discussion paper are timely, and strongly supported throughout the community and government, for five primary reasons:

- there is a growing concern about the adequacy of the existing legislation (especially the *Patients Property Act*) and systems to deal effectively and fairly with a rapidly aging population;
- changes in the provision of health care and residential care for people with a mental handicap, mental illness, severe physical disability or head injury have resulted in reduced use of institutions and hospitals and increased use of community-based care and treatment alternatives;
- there is a growing concern about the abuse, neglect or self-neglect of some older adults or people with disabilities or illnesses who are living in their own homes or those of relatives, or who reside in care facilities;
- the advent of the Charter of Rights and Freedoms has brought with it the need to review and amend any legislation that affects the right to liberty or a person's equality rights (e.g., the *Patients Property Act*); and
- there is increasing criticism of existing legislation and systems affecting substitute decision-making and guardianship, particularly on the part of the organizations representing the interests of people with a mental handicap or mental illness.

These concerns are driving, and have driven, similar reforms in other Canadian jurisdictions, notably Saskatchewan, Quebec, Ontario, and Yukon.

Events unique to British Columbia have also provided an impetus for the reforms outlined here, including the concurrent review of the *Mental Health Act* and the recommendations made by the Mental Health Act Review Consultation Committee, and some of the recommendations made by the Royal Commission on Health Care and Costs, chaired by Mr. Justice Seaton.

Four members of the Joint Working Committee — Dr. Robert Gordon, Mr. Gerrit Clements, Mr. Mark Perry and Dr. Garry Curtis — are also members of the Mental Health Act Review

Consultation Committee. In addition, members of the Project to Review Adult Guardianship met with Mr. Justice Seaton and other members of the Commission at an early stage in the Committee's deliberations. Readers of the Royal Commission's report, *Closer to Home*, will note that matters covered in this discussion paper (e.g., the introduction of legislation governing substitute consent to health care) were considered by the Commission as being within the mandate of this review.

PRINCIPLES

This discussion paper sets out the individual components of a new approach to providing adults with support, assistance and protection. These components are a marked departure from the existing legislation and procedures which tend to reflect a Victorian philosophy of benign paternalistic intervention.

The proposals in this paper are based on a century of advances in knowledge and understanding, and on five fundamental principles:

Principle 1:

All adults have the right to autonomy and self-determination and the right to enjoy the fundamental rights and freedoms prescribed in the *Canadian Charter of Rights and Freedoms*.

Principle 2:

All adults are entitled to receive the most effective but the least restrictive, least intrusive, and least stigmatizing form of assistance, support or protection when they are unable to act independently, or interdependently care for themselves or for their property and financial affairs, particularly where there is a risk that the adult will be subjected to abuse or neglect.

Principle 3:

All adults are entitled to the legal presumption that they are capable of making decisions and, where necessary, to support and assistance in order to understand and make informed decisions on their own behalf.

Principle 4:

The use of court procedures and court orders appointing decision-makers or Guardians for adults should occur only as a last resort and only after alternatives such as the provision of supports and assistance have been either attempted or carefully considered.

Principle 5:

All procedures, protocols and other processes associated with the provision of support, assistance, or protection shall be intellectually, psychologically, physically, culturally, and financially accessible to all adults.

ORGANIZATION

The chapters that follow contain discussions of the various components of the proposed new model of support, assistance, and protection.

The first three Chapters each reflect a different attempt to provide for genuine and innovative alternatives to court-ordered decision making or guardianship.

Chapter One (Personal Support) describes the invaluable role of family and friends in providing informal support and assistance to adults. The model set out in Chapter Two (Advocacy) recognizes the importance of self advocacy and reinforces the importance of family and friends acting as advocates. The concept of the Representation Agreement — a document that any adult may complete at any time to plan for or put in place associate or substitute decision making with regard to his or her personal and financial matters — outlined in Chapter Three may prove to be the single most popular and effective option.

These first informal, least intrusive components are supplemented by more formal procedures and resources in the chapters that follow.

Chapter Four (Abuse, Neglect and Self-Neglect) outlines procedures and methods for responding effectively and fairly to cases of abuse, neglect, or self-neglect. This is an extremely sensitive area where an adult's rights to receive support, assistance and protection and to refuse such intervention needs to be balanced.

Chapter Five (Consent to Health Care) presents proposals for new legislation and procedures affecting substitute consent to health care and treatment. This component is also of great significance as a mechanism for avoiding court-ordered guardianship. Court-ordered guardianship is often sought unnecessarily, primarily because the law that governs informed consent and substitute consent to health care in this province is unclear. The proposed changes should help to eliminate the current confusion and more effectively protect the rights of both health care consumers and health care providers.

Because interventions without the voluntary involvement of an adult are necessary in some circumstances, Chapter Six (Capacity and Needs Review) presents a number of proposals for establishing a mechanism to review an adult's decision making capacity and his actual need for someone else to make decisions on his behalf. Such a review may find, for example, that the adult may lack the capacity to make decisions in certain areas but, because of effective and committed supports, may not need the assistance of a court-appointed substitute decision maker or Guardian.

Chapter Seven (Court-Ordered Decision Making and Guardianship) includes proposals for new provisions and procedures governing the appointment and removal of court-appointed decision makers and Guardians and their powers and duties. These proposals are designed to ensure that court orders are sought only as a last resort, and that adults retain their decision making powers to the greatest extent possible. To achieve this, we have set out additional proposals for establishing a variety of different levels and forms of decision making intervention, designed to ensure that the adult retains his fundamental rights to the greatest extent possible while still receiving the support, assistance, or protection he needs.

Chapter Eight (The Office of the Public Guardian and Trustee (OPGT)) proposes a new organization for the existing Office of the Public Trustee, designed to support and enhance the

system of care outlined in this discussion paper. The proposed Office of the Public Guardian and Trustee will combine the concepts of guardianship and trusteeship in an integrated model of service delivery and will be held fully accountable to the public through a community Advisory Board, regional Consumer Advisory Committees and a yearly public audit.

CHAPTER 1
PERSONAL SUPPORT

SUMMARY

The best guarantee of a rich and secure quality of life for any adult is the active involvement of caring and committed people in her life. Family and friends generally provide this support and they are also a natural source of assistance for adults who experience difficulty in making decisions about their lives.

Quite often, the biggest disadvantage facing adults who are the focus of this discussion paper is their isolation from family and the community. In many instances, this isolation can be reduced by encouraging the participation of family, friends and acquaintances in the adult's life. For people without natural supports, the isolation can be addressed by creating and maintaining a network of personal support or by connecting the adult to the larger community.

A strong network of personal support significantly enhances an adult's ability to maintain her autonomy and self-determination. A strong network of personal support can also be a critical and contributing factor in establishing an adult's capability. Therefore, personal support should form the foundation on which decisions about the need for more formal social and health services, legal protection and guardianship are made.

The role and importance of personal support are recognized throughout this discussion paper. For example, Representation Agreements provide the opportunity for adults to nominate people from their circle of support to become their representatives. Similarly, a new form of court appointed decision making, an associate decision maker, makes provision for joint decision making between an adult and her supporters.

In other systems and procedures, we have ensured that the adult's family and friends will be invited to participate in the adult's life to the fullest extent possible, and that they receive the education, information, connection with others in similar situations, and support they need to assist the adult, especially during crises.

For adults whose natural support systems are limited or have broken down, we have also incorporated into our model, systems and procedures for the creation, enhancement and maintenance of a personal support network — variously called "Circle of Friends", "Personal Network", "Mini-Board" or "Ulysses Committee".

Strengthening the personal support systems of vulnerable adults should become a priority in our society. In order to encourage the participation of informal personal support or to facilitate its formation for adults who are the focus of this discussion paper, we propose that the professional community and the larger system of care in this province also adopt procedures that:

- accept and encourage the adult's family and friends to participate in the adult's life to the fullest extent possible;
- support the creation, enhancement or maintenance of networks of personal support.

CREATING PERSONAL SUPPORT WHERE IT NO LONGER EXISTS

As noted above, families and friends are a natural source of assistance for adults who find it difficult to make decisions about their lives.

For some adults, however, the naturally occurring circle of support is either limited or may no longer exist, forcing them to rely solely on more formal social and legal support systems. These systems include a wide range of human services, professional support and social, health and educational programs, in addition to legislated protection and guardianship.

While useful as a supplement to natural sources of support, these formal systems do have a number of limitations. For example:

- funding for programs and services is often limited and is coming under increasing restraints;
- programs and services cannot respond to every area of human need, particularly for friendship and companionship;
- too much emphasis on either human services or legal intervention can prevent or isolate the adult from naturally occurring family and community supports;
- guardianship is sometimes used by default when services and natural supports are not available; and
- the protection of an adult can become an end in itself rather than a means to enhancing the quality of the adult's life.

Fortunately, the knowledge and expertise to create, restore and maintain personal support networks now exist in B.C.

These formally created networks, termed Personal Networks, are groups of people, including family, friends, acquaintances and professionals, who make a long term commitment to assist the adult to lead an enriched and meaningful life.

With the adult's permission and participation, members of the Personal Network work together to:

- support the adult's plans;
- help the adult carry out functions she may be unable to carry out on her own;
- be a sounding board;
- assist the adult to understand and communicate;
- provide friendship and emotional support;
- connect the adult to the larger community; and

- advocate on the adult's behalf.

The assistance provided by the network will reduce the adult's isolation and provide an opportunity for her to achieve her goals and dreams.

Supporting the involvement, or the creation where necessary, of Personal Networks involves more than just acknowledging their importance. The OPGT will encourage the creation of Personal Networks for isolated adults under its responsibility, wherever appropriate.

Question

Do you favour the OPTG using the resources of adults who are under its responsibility to finance the creation of Personal Networks?

Do you feel the OPGT should fund the creation of Personal Networks for adults under its responsibility who do not have the resources to pay the cost themselves?

CHAPTER 2
ADVOCACY

SUMMARY

People speaking for themselves is the most important form of advocacy. However, while we recognize the right of adults to be their own advocates, we also recognize that many adults may need the support and assistance of others to understand their circumstances and make informed decisions and choices.

This support and assistance will generally come from family and friends, but there are times when it is not appropriate or possible for family and friends to act in an objective advocacy role. Then, adults must have the right to select an advocate to speak on their behalf.

To ensure that advocacy services are available to all adults who need them, we propose that:

1. Existing community-based advocacy groups be utilized and any necessary mechanisms for communication and coordination between them be developed.

2. Existing community-based advocacy groups work to recruit and train advocates and provide information to the community on the model outlined in this discussion paper.

3. Notwithstanding the right of adults to advocate for themselves, adults be asked if they would like the assistance of an advocate at five different key points in the model outlined in this discussion paper.

PRINCIPLES

These proposals are based on three primary principles:

- all adults have the right to make their own decisions and to speak on their own behalf;
- all adults have the right to a full explanation of the procedures, policies and laws which affect them; and
- all adults are entitled to whatever support is necessary to ensure that they understand the choices available to them, and must be given every opportunity to exercise their right to make informed decisions.

ADVOCACY AT FIVE KEY POINTS

An adult will be asked if he would like the assistance of an advocate at five key points in the model set out in this paper:

1. **Consent to Health Care and Treatment**

   When the adult's decision-making capability is being assessed and during appeals to the review board (see Chapter Five).

2. **Abuse, Neglect and Self-Neglect**

   During the investigation of a report of abuse, neglect or self-neglect; at the time a Capacity and Needs Review is undertaken; throughout interventions attempting to resolve a case of abuse, neglect or self-neglect; when a support and assistance plan is being developed; when the court makes an order for intervention, and the subsequent appeal process (see Chapter Four).

3. **Capacity and Needs Review**

   During the Capacity and Needs Review (see Chapter Six).

4. **Court Process**

   During the initial inquiry; at the point of notice; during the court process; and during review or appeal processes (see Chapter Seven).

5. **Representation Agreements**

   At the time a Representation Agreement is designed, to articulate the adult's wishes and needs in the document; when revoking or altering the agreement; during an objection to a revocation or alteration (see Chapter Three).

COORDINATING EXISTING ADVOCACY SERVICES

In the model we envision, existing community-based advocacy organizations will work together to coordinate advocacy services at the community level, and will:

- support and train adults to act as their own advocates, or support and train family members and friends performing the advocate role;
- recruit, train and monitor advocates; and
- provide legal or general advice to advocates upon request.

Some existing advocacy agencies will also provide general public information about the model of guardianship outlined in this discussion paper. Other agencies may develop information for special consumer groups.

[NOTE: We envision that this public education and information role will be funded and supported by the Office of the Public Guardian and Trustee (see Chapter Eight)].

QUESTIONS:

Is there a need for a provincial organization to support the community-based agencies and:

- **encourage the development of standards and protocols consistent with guardianship principles;**
- **develop specialized education and training for advocates;**
- **provide support and consultation to member organizations;**
- **impart the principles, attitudes and philosophies contained in this discussion paper; and**
- **secure and dispense funding to the community advocacy groups?**

If so, is funding needed for this central agency?

Should the Office of the Public Guardian and Trustee (OPGT) be obliged to provide funding for advocacy at the five key points described above, or should funding be provided by an alternative and fully independent source, such as the Ministry responsible for human rights?

THE ROLE OF THE ADVOCATE

Where the adult chooses to advocate on his own behalf, his decision will be respected. Where the adult wishes assistance, he will have the right to choose whom he would like to assist him.

In many cases, the adult will choose a family member or friend. This family member or friend will be offered information and assistance from the existing community-based advocacy groups.

If the adult wishes assistance and does not have anyone he can identify to act as his advocate, the adult will be offered a choice from a list of trained advocates provided by the existing community-based advocacy groups.

The advocate — whether a family member, friend or trained advocate from the Advocacy Network — will:

- explain any part of the process which affects, or is likely to affect, the adult;
- make sure the adult has all relevant information about his rights and entitlements in the process;
- articulate the adult's wishes in the process;
- ensure that the alternatives to guardianship and substitute decision-making are investigated;
- monitor the process to ensure the adult has access to safeguards and appeal procedures; and
- act to resolve problems and ensure that the adult's wishes are respected.

The assistance of an advocate does not preclude access to direct legal representation when needed. Where the adult is unable to afford these legal fees, the cost will be borne by the legal aid tariff.

CHAPTER 3
REPRESENTATION AGREEMENTS

SUMMARY

Discussions with — and submissions from — a number of interested groups and individuals have indicated significant support for expanding and restructuring the existing enduring Power of Attorney in order to include health and personal care decisions in addition to legal and financial decisions, and to:

- provide a pre-planning mechanism which is easily understood and arranged, yet includes safeguards necessary to prevent abuse;
- allow any adult to prescribe, in as much detail as she wishes, the nature, scope and time frame of her Attorney's powers and areas of authority; and
- incorporate the concepts of a variety of informal agreements currently in general practice, including personal support networks, living wills, advance directives, health care proxies, Ulysses Agreements and psychiatric wills.

In order to integrate these characteristics, and to create an alternative to the use of court-appointed decision makers and Guardians, we propose that:

1. Legislation for enduring Power of Attorney be repealed and new legislation be enacted that will allow any adult to draw up a "Representation Agreement."

   This Representation Agreement will:

   - allow the adult to voluntarily select and empower one or more people to assist, support, act or make decisions on her behalf, when she is no longer capable of making decisions independently;
   - allow the adult to indicate that this form of support and assistance is to begin immediately, or at a particular time in the future;
   - empower the adult's designated representative(s) to make decisions on her behalf in personal and health care matters, in addition to legal and financial decisions; and
   - recognize the general concepts found in the range of informal agreements, such as personal support networks, "living wills," advance directives, health care proxies, Ulysses Agreements, and psychiatric wills.

2. This new legislation be supported by a well-planned — and adequately funded — program of public and professional education.

PRINCIPLES

Representation Agreements shall be based on three primary principles or concepts:

Presumption of Capability

Communication techniques and needs differ with each individual. We cannot assume that an adult is not capable of entering into a Representation Agreement simply because we have difficulty understanding her methods of communication.

Every adult shall be presumed to be capable of making decisions about personal and health care, legal and financial matters, and about activities of daily living, until the contrary has been proved to the satisfaction of the court.

Where possible, the adult will be given the assistance necessary to help her understand the concept of a Representation Agreement, and to help her communicate that understanding (see Chapters One and Two).

Standards of Capability

The following four factors should be present and will be weighed when determining whether an adult has the capability to enter into an Agreement:

- the adult has communicated a desire to have the representative(s) make or help make decisions about health care, finances or activities of daily living;
- the adult has demonstrated choices and preferences and can express feelings of approval or disapproval of others;
- the adult is aware that entering into a Representation Agreement means that the representative(s) will make decisions or choices which affect her;
- the relationship between the adult and the representative(s) is one of mutual trust, acceptance, commitment and caring.

Decision-Making Rights

In appointing a representative, an adult will not abandon her right to make decisions, but will rather share that right with her representative. The adult sharing her decision making right means, in effect, that a third party — such as a bank or a physician — may choose to act upon a decision made by the adult's representative, even when the adult disputes that particular decision.

If there is a dispute between the adult and her representative, the adult may revoke the Agreement as long as she has the capability to revoke. If there is a dispute and the adult is not capable of revoking the Agreement, the Agreement will remain valid although it may be appropriate for the dispute between the representative and the adult to be mediated. If the representative and the adult cannot resolve the dispute, the representative will be able to apply for a court order appointing a decision maker or Guardian.

PROCEDURES

THE DOCUMENT

A standard Representation Agreement document, pre-tested by lawyers, notaries and community groups for ease of use, will be developed.

SIGNING AND WITNESSING

The Agreement must be in writing and must be signed by the adult, in the presence of two witnesses.

A witness will be required to sign a certificate affirming that he or she is 19 years old or over, has asked for confirmation of the adult's identity, and that the adult has signed the Agreement in her presence. The witness will also confirm that the adult has told the witness that she has read the Agreement or has had it read to her.

The following people will not be permitted to act as witnesses:

- the representative;
- the spouse, partner, child or parent of the representative; and
- an employee (manager, agent) of the representative.

[NOTE: If it is later determined that these witnessing requirements have not been followed, the Agreement will be subject to cancellation by the court. Anyone may apply to court to confirm the validity of the Agreement; the court will determine who will bear the costs of this application.]

The witness is to be someone who can understand any form of communication used by the adult. That way, if it is difficult to understand the adult, the adult may sign or place a mark on the Agreement in the presence of the witness who will confirm the adult's intention to enter into the Agreement.

If the adult is physically incapable of signing the document, it may be signed by another person. This signer should, if possible, know the adult and:

- must sign on behalf of the adult in the adult's presence and under the direction of the adult;
- must not be the representative(s), but can be one of the two witnesses; and
- will be required to complete a certificate verifying that the adult has directed the signer to sign on her behalf.

CHOOSING THE REPRESENTATIVE

The adult may choose any individual or the Office of the Public Guardian and Trustee (see Chapter Eight) as her representative.

For financial and legal matters only, the adult may choose a corporation or society from a prescribed list set out by the Attorney General.

QUESTION:

Should an adult be able to appoint a corporation or society as representative for health and personal care decisions, in addition to legal and financial affairs?

The adult should be careful not to choose a representative who is likely to be in a conflict of interest with her; the representative should not accept the appointment if there is likely to be a conflict of interest.

The adult may also choose more than one person to be the representative. In such a case, the adult should be careful to select carefully to avoid potential conflicts among the representatives.

The adult may choose to assign a specific authority to each individual within a group of people acting as her representatives. The Representation Agreement should specify who is the spokesperson or key representative, and a method for resolving any conflicts.

THE ROLE OF THE REPRESENTATIVE

Once the adult has chosen a representative, the representative must sign a certificate affirming that she accepts the role of representative and understands that the requirement of the position is to act in accordance with the instructions set out in the adult's Representation Agreement. The certificate will also state that the representative may be liable for any decisions not made diligently, honestly and in good faith.

The representative must also understand the Agreement registration process and must know:

- what to do if a conflict of interest arises;
- how to give notice to the adult in the event of conflict of interest;
- procedures for terminating the Agreement; and
- that there is no fee for being a representative, unless otherwise specified in the Agreement, but that the representative is entitled to reimbursement for out-of-pocket expenses.

If the representative or her family personally benefits from a decision made on the adult's behalf, the representative may be questioned, challenged or held accountable.

Where a conflict of interest arises, the representative must notify the OPGT of that conflict.

The representative may retain professionals such as lawyers, investment counsellors and accountants to assist in the management of the adult's property and financial affairs.

SELECTING AN ALTERNATIVE REPRESENTATIVE

The Representation Agreement should provide for the selection of an alternate representative. The Agreement must set out the specific circumstances under which the alternate representative will have the authority to act.

The alternate would act when the representative is unable or unwilling to act, or when the representative has died.

If the alternate assumes the role of representative, the Agreement terminates upon the death of the alternate or when the alternate refuses to continue to act.

APPOINTING A MONITOR

The Representation Agreement shall provide for a person of the adult's choice — or the adult's nearest relative — who is willing and able and not already the representative, to be a "monitor".

The monitor shall be named in the Agreement and informed of that fact. The monitor must agree to act as monitor and acknowledge her willingness to act, in writing.

The monitor has the power to:

- call for a report from the representative if there are reasonable grounds to believe that the representative is not exercising her powers or carrying out her duties properly; and
- to visit the adult in person at any reasonable time and despite the objections of the representative.

The monitor has the duty to report any wrong doing to the OPGT if the monitor cannot persuade the representative to act in accordance with the Agreement and the prescribed duties.

If the adult does not designate a monitor, the OPGT will automatically act as monitor. If the adult does not wish to have a monitor, she must specify this in the Agreement.

A representative or any other interested party may apply to court for the replacement of a monitor if there are reasonable grounds to believe that the monitor is no longer acting as a monitor or is otherwise unsuitable. In such cases, the OPGT will be the default monitor.

If the monitor acts diligently, honestly and in good faith, the monitor shall not be held liable for the actions of the representative.

POWERS AND DUTIES

A standard Representation Agreement will limit the representative to assist, support, or to act on the adult's behalf in:

- routine activities of daily living, including where the adult is to reside and with whom;
- routine financial management;

- routine health care and treatment; and
- securing legal services.

The adult may add to, or remove something from, this list.

However, any modification of the standard Agreement must be in writing. These modifications may, for example, authorize the physical management of the adult by her representative, prescribe that the representative is to consent to psychiatric treatment of a particular type under specific circumstances and, even though the adult is refusing consent to treatment at the time it is required, specify that particular kinds of treatment shall not be given, require that only particular kinds of treatment shall be given, and so on. A modification may also authorize the representative to make substitute decisions for the adult.

In order to assist, support, act or make substitute decisions on the adult's behalf, the representative will first consult with the adult to determine her current wishes. If the representative cannot determine the adult's current wishes, or if her current wishes are inconsistent with her pre-expressed wishes, values, beliefs and preferences or her best interests, the representative will act and make decisions according to the adult's pre-expressed wishes, if known. (Pre-expressed wishes are the adult's wishes as stated in a document or expressed verbally to the representative at a previous time.)

If the adult's pre-expressed wishes are not known, the representative must make decisions in a manner consistent with the adult's values, beliefs and preferences. If these are not known and cannot be ascertained, the representative will make decisions in the adult's best interests.

The representative is not obliged to follow the adult's current wishes or pre-expressed wishes where to do so is impossible, or against the law. If the representative makes decisions in accordance with the adult's wishes, and there is loss or damage to the adult's estate, the representative should not be held liable.

If the adult's instructions do not make it clear to the representative how, or if, the representative can make a certain decision, the representative may seek guidance from the OPGT.

If the problem cannot be resolved, the representative may apply to court for instructions, direction, or interpretation. The court may make an order which the court believes is in the best interests of the adult. The court may order that the costs of an application be paid from the adult's estate.

LIMITS ON POWERS AND DUTIES

The adult may authorize her representative to make decisions respecting her property and financial affairs and her personal care, health care (including medical and psychiatric treatment), the temporary care and custody of — and payment for — her minor children. The adult may also authorize her representative to refuse life-supporting care and treatment.

The representative should have the authority to deal with legal matters, and may institute legal proceedings or defend legal actions on behalf of the adult.

The standard Representation Agreement will provide for investment powers as set out

under the *Trustee Act*. The adult may choose to modify these investment powers in her Representation Agreement.

QUESTION:

Are there certain decisions that should not be delegated to a representative?

The legislation should probably reaffirm existing rules (e.g., with respect to voting, marriage, and the making of wills), and perhaps set out additional prohibitions. For example, should a representative be able to institute divorce proceedings; consent to the adoption of the adult's minor children; consent to psycho-surgery and other forms of controversial and irreversible treatment such as non therapeutic health care and experimental treatment?

The representative should be under a duty to keep financial records and to produce these to the adult, the person appointed as "monitor," or the OPGT on request.

The representative has the right to receive information from medical practitioners, consult appropriate people, ask for second opinions, and be fully informed, just as if she were the adult, and in order to make a fully informed decision.

In all cases, the adult will always have the ability to act simultaneously with the representative and is able to revoke the Agreement as long as she is capable of revoking it.

THE TRIGGERING EVENT

A standard Agreement will come into effect immediately, but the adult may modify the agreement and decide that it shall come into effect at a future time. This event is called the "triggering event."

The adult may choose whether the authority of the representative is to be effective either when:

- the report of a Capacity and Needs Review indicates that the adult is not capable of making certain decisions; or
- a pre-designated event occurs (e.g., the adult is admitted to hospital).

If the triggering event is the outcome of a Capacity and Needs Review, the adult may wish to give prior consent to a Capacity and Needs Review as part of the Representation Agreement (see Chapter Six).

If the Review indicates that the adult is not capable of making certain decisions, the representative must attach a basic and limited statement of the Review's results to the Agreement in order to provide the necessary information without violating the adult's right to privacy.

The Review may determine that the adult is capable of making some but not all decisions, and the representative would have to know explicitly which decisions these are. The report of the Review should clearly specify these areas so that any third parties (anyone who is relying on the representative to make a decision) would know when the representative has the authority to act.

When a representative has received confirmation that the pre-designated triggering event has occurred, a certificate of this confirmation must be attached to the Agreement. It is the responsibility of the person who is being asked to accept the authority of the representative to ensure that the Representation Agreement is effective.

If the triggering event is not a finding of incapability following a Capacity and Needs Review, the prescribed event must be clearly set out. The representative must have some proof or authentication to show to any third parties that the triggering event has occurred.

REGISTERING AGREEMENTS

To become effective, a Representation Agreement must be accepted and signed by the representative, then registered with the Representation Agreement Registry. The Representation Agreement Registry will be part of an on-line computer network, with 24-hour access.

To register an Agreement, the original or a copy of the fully executed Representation Agreement and representative(s) certificates must first be forwarded to the Registry. The Registry will then:

- review the documents and confirm that the documents have been properly executed;
- record the names, addresses and phone numbers of the adult, her representative(s) and alternate(s) and the form of any triggering event(s); and
- return the documents to the person — either the representative or the adult — who sent them in;

The Registry will also record any notice that an Agreement has been changed, revoked or terminated.

The information lodged with the Registry will:

- ensure that third parties have a method of confirming that the representative has authority to act and at what decision-making level;
- make it easy to find the representative at a time when a decision must be made; and
- make it possible to introduce a system for challenging the use of Agreements.

If the Agreement is to become effective immediately, a seal will be placed on the document.

If the Agreement is to be triggered at a later date, the representative is responsible for proving to the Registry — at that later date, through a Capacity and Needs Review report or with a sworn statement — that the triggering event has occurred. A seal will then be placed on the original Representation Agreement to officially trigger the document.

In certain circumstances, the Representation Agreement will need to be triggered and acted upon in a very short period of time (e.g., when a adult enters hospital and requires immediate treatment). In such a case, the Representation Agreement will be deemed to be effective when the triggering event is met and the authority of the representative to act is confirmed through an on-line search.

Access to Registry information will be strictly limited to reasonable inquiries in order to protect an adult's right to privacy. There will be a small charge for the registration of Agreements, to be paid by the adult, to cover basic administration costs.

QUESTION:

Should the Registry provide more services than we have outlined here?

For example, the Registry could also provide a review service to ensure that a proposed Agreement sets out a level of authority and a triggering event that fully meets the adult's needs.

CHALLENGING AN AGREEMENT

Any person may challenge a Representation Agreement. Most challenges will probably occur either at the time the Agreement is registered or at the triggering event.

A challenge may be launched on one of seven grounds:

- the adult did not have the capacity to enter into the Agreement (e.g., the adult was under the influence of drugs or alcohol, actively psychotic or experiencing severe dementia);
- there has been a procedural error or impropriety;
- fraud or undue pressure was used to induce or trigger the Agreement;
- where the representative is acting without the authority of a triggering event;
- the Agreement is clearly inconsistent with the adult's current wishes, values, beliefs, etc.;
- there is clear evidence of abuse or neglect by the representative(s); and
- the decisions are not being made in accordance with the wishes of the adult.

A challenge must be registered with the OPGT, and a notice must be sent to both the adult and the representative.

Upon receiving the notice, the representative has 28 days in which to resolve, withdraw, settle or agree with the challenge. If the representative does not file a reply to the notice, the Agreement is automatically revoked at the end of the 28-day period. The representative shall be warned that she is liable for any loss or damage resulting from any decision taken on behalf of the adult during the 28 days.

If the challenge is not resolved, the OPGT may apply — or assist another person to apply — for a court order appointing a decision maker or Guardian.

In cases of abuse, the Community Response Network (see Chapter Four) shall respond to the matter during the 28-day period.

UPHOLDING A REPRESENTATION AGREEMENT

If it seems possible that a Representation Agreement may be challenged at some time in the future, the adult and the representative should gather material to confirm where possible:

- the adult's thinking ability, intentions, feelings, motives, and social capability;
- the presence of committed, accepting and reciprocal relationships and belonging to a group, family or network;
- the adult's understanding of the general purpose of the agreement, particularly with respect to legal, health and personal areas, at the time she entered into the Agreement;
- the committed, accepting, and trusting relationship with the individual named as representative;
- previous joint decision making in personal, financial, and medical areas between the adult and the representative(s); and/or
- that the adult entered into the agreement on her own initiative or free will.

THIRD PARTY LIABILITY

A representative who acts according to the authority that has been granted in the Representation Agreement, but does not know that the Agreement has been revoked, is not liable and will be deemed to have had authority to act.

If an Agreement has been revoked or has become invalid, and another person accepts the authority of the representative, the Agreement will be considered valid for that instance. This is good as long as the other person acted in good faith and did not know that the Agreement had been revoked or voided.

COMPENSATION, REIMBURSEMENT AND COSTS

A representative or monitor is not entitled to remuneration for her services as a representative or monitor, unless expressly granted remuneration in the Representation Agreement.

The costs of all applications to court are in the discretion of the court and the court may order that the costs of the application be fully paid from the estate of the adult.

The representative has the right to be reimbursed from the adult's estate for expenses properly incurred.

REVOCATION AND ALTERATION

Any adult who is capable of revoking or altering may revoke or alter the Agreement at any time. The standard of capability for revocation/alteration shall be the same as for entering into an agreement.

When developing an Agreement, the adult may choose to shorten or extend the time period before revocation or alteration takes effect, and may also set out additional revocation or alteration criteria.

The adult must notify the Registry and the representative/ alternate of her wish to revoke or to alter her agreement. After the appropriate time period, the adult may register the revocation or alteration. If the representative does not challenge the revocation, it is effective upon registration.

The standard Agreement shall indicate that a revocation will be effective 72 hours after notice has been filed with both the representative and the Registry.

There will be a fee for the registration of revocations or alterations.

CHALLENGING A REVOCATION OR ALTERATION

There are only three grounds for challenging a revocation or an alteration:

- that the adult does not have the capacity to revoke or alter the agreement;
- fraud or undue pressure was used to induce the revocation or alteration; or
- any additional grounds set out in the Representation Agreement with respect to revocation or alteration.

In the event of a challenge, the OPGT will review the challenge to determine whether or not the challenge is valid.

The OPGT shall, to the greatest extent possible, attempt to uphold the adult's decision to revoke or to alter the Agreement, including the provision of mediation services to resolve conflicts between parties.

If mediation fails and a challenge continues, the OPGT may apply — or assist the adult to apply — for a court order confirming the revocation or alteration or any other order deemed appropriate by the court.

TERMINATION

A Representation Agreement is terminated:

- upon the appointment of a decision maker or Guardian by the court;
- after the appropriate notice period and receipt by the Registry of a written revocation;
- upon the death of the adult;

- upon the death, bankruptcy or incapability of the representative unless an alternate has been appointed;
- upon the dissolution of marriage if the adult and the representative were spouses; or
- by court order.

All terminations must be registered.

INVESTIGATION AND REVIEW

The OPGT will develop a process to deal with situations where concern has been expressed about the way in which a representative has carried out her responsibilities (e.g., dealing with allegations that a representative is inappropriate because she has not had contact with the adult for many years).

The OPGT shall have investigative powers concerning the accounting and management of the adult's affairs and may take specific action, including obtaining a court order revoking the Agreement. In this situation, the alternate representative may act or an application may be made to court for the appointment of a decision maker.

OTHER JURISDICTIONS

Provision shall be made for accepting a document similar to a Representation Agreement from another jurisdiction. The document will be reviewed by the OPGT and then registered in B.C.

ADDITIONAL CONSIDERATIONS

INSTRUCTION GUIDE

While it would be advisable for lawyers and notaries to draw up Representation Agreements, some people may want to prepare their own documents.

An Instruction Guide will be developed for use with Agreements. This Guide will be written in clear and plain language and will include:

- information about the rights and responsibilities of the representative and the adult;
- information about how to create a Representation Agreement, with step-by-step instructions for each section of the Agreement;
- an explanation of the manner in which the representative should make decisions;
- recommendations that the adult review the details of the Agreement with the representative at the time of the appointment; and
- phone numbers for resources and further information.

In addition, the OPGT should provide materials and training seminars for prospective representatives so that they are better able to make decisions for the adult.

THE EDUCATION OF FACILITIES, PROFESSIONALS AND THE PUBLIC

We suggest that special provision be made to dispel uncertainties and to ensure that agreements are respected in practice, particularly with respect to hospitals and care facilities.

Administrators should maintain written policies and procedures to encourage adults to enter into Representation Agreements, provide information concerning representation agreements to each adult on admission and on discharge, document in the adult's record whether or not the adult has made an agreement, and provide for the education of staff and others involved with the care of the adult on issues concerning agreements.

Members of the professions most likely to encounter adults who wish to complete and to use Agreements (e.g., in the law, medicine or social work fields) should receive special professional education on the creation and use of Agreements.

We strongly recommended that the provincial government provide funds for a campaign to inform the public and to encourage the use of representation agreements. The campaign should involve the organizations representing the interests of the adults most affected by Agreements and should include the production of plain language brochures and other information for distribution to adults. Other educational strategies could include the use of the People's Law School and the services of private sector financial and retirement planners.

CHAPTER 4
ABUSE, NEGLECT AND SELF-NEGLECT

SUMMARY

Health, justice and social services agencies have begun developing protocols to address the abuse, neglect and self-neglect of adults. These protocols attempt to define the problem and to instruct staff on how to respond, but there are certain limitations in the current system:

- it lacks coordination and focus;
- it is unclear who must report or who has the authority to receive reports;
- staff have limited training and resources to deal with complex cases; and
- there is limited authority to act when the adult requires protection as it is not possible to legally intervene.

In our view, there are three primary options available to correct these limitations: either we establish a new agency to handle abuse, neglect and self-neglect cases exclusively; or we designate an existing agency as the sole provider of services in these cases; or we find ways to improve and coordinate the services offered by existing community agencies.

We favour this last option.

Community services are often an effective way of preventing or stopping abuse, neglect or self-neglect of adults, and, in order to strengthen and build on the existing response system at the community level, we propose that:

1. Each community develop a local Community Response Network (CRN), comprised of all agencies with a mandate to deal with the health, justice, and social issues of abuse, neglect and self-neglect.

2. These local CRNs be supported by a designated central support agency, which will also be responsible for setting provincial protocols and standards.

3. That members of the CRNs receive funding to coordinate staff training and provide information to the community.

4. Legislation be amended to allow agencies greater authority to intervene when an adult needs protection from abuse, neglect and self-neglect.

These proposals are based on the belief that capable adults have the right to choose to accept assistance or to live at risk. Where the adult's capacity is in question, the adult must first be offered support and services which would maximize his or her chances of remedying the situation without formal intervention.

Where an adult is found to be incapable of decision making specific to this area of his life, refuses protection, and yet there is clear evidence of abuse, neglect or self-neglect, additional authority must be available as a last resort to intervene and protect the adult.

The system we propose will ensure that all cases receive a response when needed, whether that response is the offer of services or simply a referral to a more appropriate system.

Effective screening of each report will ensure that the response is specific to the particular needs of the adult, and so does not provide a response mechanism to other abuse situations, such as general spousal assault or child abuse.

[NOTE: Many community agencies deal with a mix of clients; some individuals will fall within the mandate of this report and some outside its focus.]

PRINCIPLES

Our proposals for amended legislation and the activities of CRNs are based on five basic principles:

- an adult is entitled to live in any manner he wishes, so long as it can be determined that it is the adult's own decision, and does not cause harm to others;
- society as a whole has a responsibility to offer support to adults who are experiencing abuse, neglect or self-neglect;
- society has an obligation to protect adults who have been found not capable of making decisions about abuse, neglect and self-neglect;
- any intervention undertaken shall be the least intrusive or restrictive in nature, in order to restore power to the adult or effectively remedy the situation in the most timely manner possible, and shall be subject to review and revision as the adult's situation changes;
- there is no justification for abuse. The Criminal Code of Canada will be applied, where appropriate and consistent with the manner in which other Criminal Code matters are handled.

DEFINITIONS

The proposals set out in this chapter apply to all adults, regardless of where they live, who are experiencing abuse, neglect or self-neglect and who are not able to remove themselves because of a physical disability or diminished mental capacity.

- Abuse is used to mean mistreatment which causes an adult physical or psychological harm, loss of the adult's rights or loss to his estate. This includes:
- financial or material abuse, such as unauthorized use of bank accounts or property;
- psychological or emotional abuse, such as intimidation, humiliation, treating an adult like a child;

- physical abuse, such as acts of violence or rough treatment;
- sexual abuse, such as any unwanted or exploitive sexual behaviour, including harassment, assault;
- medication abuse, such as withholding medication or over-medication; and
- violation of rights, including mail censorship, denial of privacy or access to visitors.

Certain forms of abuse may be offenses under the Criminal Code of Canada. However, the definitions of abuse are not limited to criminal acts.

- Neglect is the failure to provide the necessary care, assistance, guidance or attention to an adult, and which results in physical or psychological harm or loss to the adult or his estate. Neglect may be caused by an action or simply a failure to act, and may be intentional or not.
- Self-neglect occurs when an adult is living in grossly unsanitary conditions, suffering from an untreated illness, disease or injury, or suffering from malnutrition to the extent that if intervention does not occur, the adult will likely suffer harm leading to severe and long-term impairment of his mental and/or physical health, or to death.

Self-neglect also occurs when an adult creates a demonstrably dangerous situation that will likely cause physical or psychological harm or loss to the adult, to his estate, or to others. A demonstrably dangerous situation may include the dangerous use of appliances leading to fire or injury.

QUESTION:

Is this definition of self-neglect sufficient?

- Community agency refers to any agency with a mandate to deal with the health, justice and social issues of abuse, neglect and self-neglect.

COMMUNITY RESPONSE NETWORKS

Existing health, justice and social services agencies in each community will work together to coordinate their activities and respond to reports of abuse, neglect and self-neglect. This cooperative undertaking will be known as a Community Response Network (CRN).

A central agency will be designated to support these local Community Response Networks across the province. This central agency will secure government funding in order to ensure that the CRNs have the support they need to operate effectively in the community, and will:

- design a model protocol and standards which can be adapted to meet the resources and needs of local communities and to which local CRNs will adhere;
- provide support and training to CRNs;

- monitor the CRNs to determine how well they are working;
- provide special case officers to deal with difficult cases and conflict situations; and
- carry out research and evaluation where appropriate.

Each local CRN will define and establish its own protocols, based on the model protocol and standards developed by the central agency. In this way, the unique needs and resources of each community will be reflected in the way in which the CRN deals with reports, but still fall within province-wide standards.

In addition, the members of each local CRN will coordinate training and support for staff, so that all staff are aware of and adhere to the principles and protocols of the system. The CRN will also undertake public education and community awareness initiatives.

While the precise nature of CRNs will vary between communities, they will have several features in common:

- The heart of each CRN will be the local protocols. These will outline who is responsible for coordination, investigation, and responses in various types of abuse, neglect and self-neglect.
- Each CRN will need to designate a certain number of core agencies. These agencies will take the lead in the major functions of the CRN (investigation, response, education), and staff in these agencies would receive training on the specific aspects of the protocols (e.g., investigation) for which they are responsible, as well as general information on the whole process.
- Each CRN will involve a second tier of agencies, required to be involved on a regular basis but which do not have a lead responsibility in the response protocol. An example of this second tier could be the role taken by alcohol and drug counselling programs, where they may be required to work with a core agency to investigate a case, but would not take the lead in the CRN protocols defined for abuse, neglect and self-neglect.
- And each CRN will work with a third tier of agencies, typically involved only in reporting and referral. A wide range of agencies will report cases or provide referrals of cases, and may also provide support to the key agencies in unusual circumstances. For example, a multicultural agency may learn of a case of elder abuse and refer the matter to the CRN. The agency may remain involved in providing language or cultural interpretation between the victim, the abuser and the CRN.

CASE TRACKING

A critical function of each CRN will be to ensure that cases which are referred from one agency to another are followed through from reporting to resolution in a timely manner.

To facilitate communication between agencies, a Central Registry Case Tracking system will be developed either locally or regionally.

The CRNs will identify which agency within the Network will be responsible for case tracking. The agency designated to perform Central Registry Case Tracking will stand separate

from the core agencies in the CRN and will ensure that any transfer of investigation or response by the core agencies is coordinated; the case is resolved in a timely manner to the extent that no further action is deemed necessary by the CRN; and that the file is closed and transferred to the registry for storage. Protocols will set out how cases are tracked while protecting the confidentiality of individuals.

REPORTING

The CRNs response will be triggered by a report of abuse, neglect or self-neglect. Realistically, this report could come from any number of sources including neighbours, relatives, homemakers, nurses, or bankers, and the person making the report may contact one or more of the agencies within the CRN.

In some circumstances, it may be difficult for the public to determine what exactly is a case of abuse, neglect or self-neglect. For this reason, members of the public should be encouraged to report cases to the authorities voluntarily, not by law.

Paid service providers, however, will be legally required to report any case of abuse, neglect or self-neglect which they observe during their work. This mandatory reporting by paid service providers should reduce any fear of job action or retaliation, which could be an issue if, for example, the person cites unprofessional behaviour by a co-worker.

[NOTE: We recognize that the Community Care Facilities Licensing Board has a mandate to investigate abuse in licensed facilities. Protocols will be developed to cover the respective roles of local licensing and CRN response.]

QUESTION:

Is it acceptable to have one standard of reporting for paid service providers and a different standard for everyone else?

One option could be to have only voluntary reporting, and to have strict confidentiality surrounding reporting so as to protect against retaliation.

Any individual reporting a case is protected from liability if the report is made in good faith (i.e., given in the honest belief that the situation fits the criteria of abuse, neglect or self-neglect). This removes any legal obligation for the person to accurately judge whether or not the case falls within the definitions of abuse, neglect or self-neglect, and also removes legal sanctions for those not familiar with the definitions who mistakenly fail to report a case.

[NOTE: To dispel doubt and encourage reporting, this protection from liability should be explicitly set out in the relevant legislation.]

RESPONSE

Every report will generate a response, although the type of response will differ depending upon the nature of the report and the initial assessment of the CRN agency receiving the report. For example:

- A decision to take no further action may be made. This is most likely to occur if the report is found to be without substance, or if the victim is an adult who is clearly capable of decision making and indicates that no action is desired.
- A report may be referred to another system if a response appears to be required but the situation does not fit the profile of abuse, neglect or self-neglect of adults. For example, a case of child abuse may be referred to an agency that is trained in dealing with such cases, but is not a part of the CRN.
- If the report falls within the CRNs mandate, the report will be referred to the CRN agency most appropriate to deal with it. Emergency situations will be dealt with immediately; non-emergency situations will be handled in two stages, beginning with an initial inquiry and possibly followed by a full investigation. Cases initially thought to be non-emergencies may be reclassified as emergencies at any time.

At any point in the initial response, an adult who is able to remedy the situation has the right to halt further action, whether or not the situation is an emergency.

EMERGENCY REPORTS

If the report is judged to be an emergency — a situation where there is substantial risk of irreparable harm to the adult's health, life or property — staff will proceed immediately using protocols developed by the local CRN.

These protocols will include offering services which have proven useful in resolving cases of abuse, neglect or self-neglect, as well as interventions designed to stop the events while a fuller investigation can be done.

Legislation will set out authority for interventions which will include:

- entering the adult's premises, if entry has been denied;
- freezing or monitoring any financial transactions for a brief period of time;
- securing personal property;
- removing or restraining the abuser;
- removing the adult to a hospital or other suitable place; and
- possibly providing medical treatment to the adult, within the parameters of health care consent (see Chapter Five).

The primary focus is the safety and well-being of the adult. Interventions are designed to ensure that any ongoing abuse, neglect or self-neglect is stopped and that the adult is able to continue with his normal way of life.

NON-EMERGENCY REPORTS

Initial Inquiry

When the report is not an emergency, CRN agency staff will proceed with an initial inquiry.

This inquiry will follow protocols developed by the CRN. Intended to be minimally intrusive, the inquiry will use only those means deemed absolutely necessary to determine whether there is sufficient substance to the report to warrant further action.

The inquiry will vary depending upon the circumstances, but may include a telephone call or a home visit. While some agencies will have staff trained in handling such initial inquiries, we anticipate that many agencies will require staff training in order to ensure that the privacy of anyone involved is not unduly compromised by the inquiry.

Early in the inquiry, staff will provide the adult with information on how to resolve the situation. This may include an offer of services or advocacy (see Chapter Two).

Where the adult accepts services and the services resolve the situation, or where the adult declines services but appears to be capable of making the required decision(s), no further action will be taken.

Where the adult appoints a representative who is willing to act on his behalf (see Chapter Three), or if steps are taken to obtain a court-appointed decision maker (see Chapter Seven), no further action will be taken.

Full Investigation

A full investigation will occur if there is evidence that abuse, neglect or self-neglect is occurring, and the adult is unable to make or carry out decisions which would remedy the situation.

The full investigation will include:

- interviews with the adult in his place of residence or in a safe and private interview room;
- interviews with the family, friends, representatives or court-appointed decision makers, and the alleged abuser;
- searching for further collateral evidence.

Some investigations will show that no further action is necessary or that, contrary to initial indications, the adult is capable of making decisions and refuses assistance. In either case, no further action would be required.

Other investigations will show that further action is required — where, for example:

- the abuse, neglect or self-neglect appears to result from social circumstances and can be relieved by offering services to both the abuser and the victim;
- the adult's health is deteriorating and he requires health care treatment;

- the adult's health is deteriorating as a result of a mental illness and he requires compulsory assessment, conveyance and detention for the illness;
- the adult is capable of making the decision and wishes to appoint a representative who is willing to help resolve the situation;
- the adult appears incapable of making a range of decisions and requires the ongoing assistance of a court-appointed decision maker;
- the abuse or neglect appears to be an offense under the Criminal Code of Canada and it is appropriate to proceed with criminal charges; or
- the abuser should be removed from the premises.

[NOTE: This list is not exhaustive and potential actions should not be considered mutually exclusive. It may, for example, be appropriate both to offer services to the adult as part of a Support and Assistance Plan (see below), and to lay charges against the offender.] Where the adult requires health or social services to resolve the abuse, neglect or self-neglect, the CRN will develop a Support and Assistance Plan specifically designed to meet the adult's area of need. Where the adult has personal support, the CRN will involve that network in the development of the Support and Assistance Plan before offering the Plan to the adult.

Adult Accepts the Support and Assistance Plan

If the adult accepts the Support and Assistance Plan, no further action will be taken.

Where consent to treatment is required, the provisions outlined in Chapter Five on consent to health care will be followed.

Adult Does Not Accept the Support and Assistance Plan

If the adult refuses the Support and Assistance Plan, and the full investigation has shown strong evidence that the adult's decision-making capability is in question and there is evidence of abuse, neglect or self-neglect, the adult's capability to withhold consent will be assessed through a Capacity and Needs Review.

Throughout this process, assistance and advocacy will be made available to the adult.

Capacity and Needs Review

The Capacity and Needs Review will focus on the ability of the adult to make decisions relevant to the abuse, neglect or self-neglect, and will occur within the environment familiar to the adult, if possible in his place of residence (see Chapter Six).

The Review will determine if the adult is capable of understanding his situation and the specific consequences of accepting or declining support and services.

If the adult resists such a Review, the adult's representative or the Office of the Public Guardian and Trustee (OPGT) will obtain a court order to conduct the Capacity and Needs Review (see Chapter Eight).

If the Capacity and Needs Review shows the adult to be capable of decision-making, no further action will be required. The adult would be considered capable of refusing the assistance and choosing to live at risk.

If the Capacity and Needs Review determines that the adult does not have the capability to make decisions which will stop the abuse, neglect or self-neglect and if the adult continues to refuse to consent to the support and assistance plan proposed by the CRN, the adult's representative, a court-appointed decision maker or the OPGT will seek an Intervention Order.

Intervention Order

The court will review the evidence gathered in the Capacity and Needs Review and decide if the adult has the capacity to make a decision on the abuse, neglect or self-neglect situation.

If the court determines that the adult does not have the capacity to make a decision, the court will order that the proposed Support and Assistance Plan be provided to the adult by the CRN without the adult's consent.

Components of the Intervention Order may include:

- hospitalization and treatment;
- care or treatment in the adult's residence;
- maintenance of property or financial affairs;
- maintenance under the Family Relations Act (financial support); or
- a removal or restraint order against the abuser.

The Intervention Order will be in effect for up to six months, and will be renewable for a further six months. Reviews may be requested by either the victim or the abuser, if either shows reasonable grounds (e.g., evidence of change in the abuser).

The Intervention Order may be appealed by either party. The appeal would delay the enactment of the Order until a decision is made.

At the end of the period for which the Order has been granted, it will automatically expire.

Where it can be shown to the court that an adult was not capable of decision making in regard to a transaction in which he gave up ownership over one or more of his assets, then the court has the authority to declare the transaction to be null and void.

CHAPTER 5
CONSENT TO HEALTH CARE

SUMMARY

Under the law right now, a capable adult may make any decision she wants about her own health care; an incapable adult must have a court-appointed Committee to make those decisions on her behalf.

However, there is currently no clear definition of when an adult is either capable or incapable of making a health care decision.

In addition, because of the time and cost involved in appointing a Committee, it has become common practice for health care providers to ask next-of-kin to authorize health care treatment on the incapable adult's behalf. These next-of-kin have no legal authority to give this consent.

In order to legally sanction the next-of-kin's authority to make health care decisions, and to more clearly define the difference between an adult who is capable of making a health care decision and one who is not, we propose that:

1. Legislation be enacted to clarify that informed consent must be obtained from an adult in either an emergency or non-emergency health care situation, provided that the adult is capable of giving informed consent.

2. If informed consent cannot be achieved, and where time permits, consent for health care be obtained from a court-appointed decision maker, representative, or temporary substitute decision maker.

3. A statutory list of temporary substitute decision makers be established, whereby consent for health care for an incapable adult may be obtained from the adult's spouse or partner or nearest relative; or the Office of the Public Guardian and Trustee.

Under this proposal, informed consent will be achieved through a process of communication between the adult and the health care provider.

Whenever an adult is faced with a health care decision, the health care provider will provide the adult with information about her condition and the risks and benefits associated with her health care options, in a manner appropriate to her skills. Where necessary, and if time allows, the adult will receive assistance in understanding this information.

An adult gives informed consent when she voluntarily agrees to the proposed treatment and demonstrates to the health care provider — in her own words or manner — that she understands:

- the information being given by the health care provider;

- that the information is being applied to her situation; and
- the specific consequences of accepting or declining the health care treatment.

The adult's consent to health care will be time limited, and will apply only to the specific medical procedure or course of treatment to which she consented. However, the health care provider may perform additional or alternative procedures if they are immediately necessary or medically advisable during the course of the procedure consented to, in order to deal with conditions not foreseen at the time consent was obtained.

If the consent given has stipulated a specific health care provider, no other health care provider may be substituted unless the procedure or treatment has already started or delay is likely to put the adult's life or health at risk.

PRINCIPLES

The proposals outlined in this chapter are based on five guiding principles:

- all adults shall be presumed to be capable;
- an adult has the right to accept or reject health care or to revoke a previous decision if she is capable of making a decision to accept, reject or revoke;
- legislation will not encourage or discourage any particular health care decision or treatment, to interfere with or to affect the adult's moral or religious beliefs or practices;
- an adult will be provided with assistance to make health care decisions through the provision of information about the health care and treatment options in a manner understandable to the adult and with, where possible, the assistance and support of people close to adult; and
- the person who will make substitute decisions on behalf of the adult will be either an individual selected by the adult or the person closest to the adult who is in the best position to make these decisions.

DEFINITIONS

The processes for health care consent set out in this chapter are based on the following definitions:

- For purposes of consenting to health care, an adult is someone who has reached the age of 16.
- Health care means procedures or treatments (including physical or psychiatric examinations, contraceptive and diagnostic procedures) provided or administered by a health care provider, and intended to diagnose, prevent, cure, improve or ease the effects of a disease, disorder, injury, ailment or other condition.
- Health care providers are people who have authority to diagnose, treat or otherwise provide health care as set out in the regulations to this Act.

- An emergency health care situation is one which is life-threatening or where failure to provide immediate treatment will likely result in serious and long-term physical impairment.

QUESTION:

Does this definition of emergency accurately reflect emergency procedures in hospitals?

- A non-emergency health care situation is divided into two sub-categories:
- Minor health care, such as any examination, minor diagnostic test, minor procedure or treatment undertaken to prevent or relieve a disease or ailment or to treat any minor injury or condition, including the provision of local anaesthetic.

  Minor health care also includes routine dental treatment, defined as oral hygiene, inspections and other examinations or tests, cavity fillings, extractions and anything done that is ancillary to such treatment — including local anaesthetic — which prevents or treats any condition or injury caused by disease or trauma.
- Major health care, such as major surgery or treatment involving general anaesthetic and major diagnostic tests.

NON-EMERGENCY SITUATIONS/MAJOR HEALTH CARE

Before a health care provider may conduct a physical examination or begin treatment of an adult in a non-emergency situation where the adult requires major health care, he or she must seek the adult's informed consent to the examination or treatment.

To achieve informed consent, the health care provider will communicate with the adult in a manner appropriate to the adult's skills, and will provide her with a description of:

- her medical condition(s);
- the proposed treatment;
- the treatment options and health care alternatives; and
- the risks and benefits associated with each treatment option (including no treatment at all).

If the adult voluntarily agrees to the proposed treatment and demonstrates to the health care provider — in her own words or manner — that she understands:

- the information being given by the health care provider,
- that the information is being applied to her situation, and
- the specific consequences of accepting or declining the health care treatment,

the health care provider will administer that treatment. If the adult declines treatment, her decision will be respected.

If the adult's response causes the health care provider to question her capacity to make the decision, the health care provider will, if time permits, seek assistance to communicate with her.

This assistance may be available from the person(s) accompanying the adult or people known to the adult who can be easily contacted. It may also be available from the adult's representative, if she has one and the Representation Agreement has been triggered (see Chapter Three), or from a court-appointed decision maker or Guardian (see Chapter Seven).

Decisions made by a representative, court-appointed decision maker or Guardian on the adult's behalf will be acted upon by the health care provider, unless legally, ethically or professionally unacceptable to the health care provider.

Where no individuals can be found to assist in communicating with the adult, or their assistance fails to resolve concerns about her capacity to make the decision, the health care provider will initiate a Capacity and Needs Review (see Chapter Six), and, at the same time, will also ask the adult if she would like the services of an advocate (see Chapter Two).

Capacity and Needs Review

If the outcome of the Capacity and Needs Review is that the adult is capable of making the needed decision, the health care provider will respect her decision.

If the outcome is that the adult is not capable of making the required health care decision, the health care provider will notify the adult's temporary substitute decision maker that he or she is now empowered to make the decision on her behalf.

[NOTE: If a Representation Agreement is triggered by a Capacity and Needs Review finding the adult to be not capable of making health care decision, the outcome of the Review will trigger the intervention of the adult's representative.]

Temporary Substitute Decision Makers

The statutory list for appointing a temporary substitute decision maker (TSDM) will consist, from the highest nominee down, of the adult's:

- spouse or live-in partner;
- child, parent, or a person who has lawful authority to stand in the place of a parent;
- brother or sister;
- any other close kin; or
- the Office of the Public Guardian and Trustee (see Chapter Eight).

A TSDM should be a person who has been in contact with the adult over the past year, and should not be in a position of conflict with the adult.

A TSDM appointed from this list will have the authority to make certain health care decisions on the adult's behalf for 21 days from the time of his or her appointment, and may apply to the court to become a court-appointed decision maker or Guardian to make ongoing decisions, if needed.

The TSDM will not have the authority to consent to controversial or experimental procedures or treatments, non-therapeutic sterilization, or research.

QUESTION:

What other limits should be placed on the TSDMs authority?

The TSDM is expected to consult with the adult in decision making to the greatest extent possible, and should follow the wishes expressed by the adult while she was capable. If the adult has not pre-expressed her wishes, the TSDM should make decisions based on the adult's beliefs and values. If the adult has not pre-expressed her wishes, and the TSDM does not know her beliefs and values, the TSDM should make decisions in the adult's best interests.

In deciding what is in the adult's best interests, the TSDM should take into consideration the adult's current wishes and whether:

- the adult's condition or well-being is likely to be improved by the treatment proposed;
- the adult's condition or well-being is likely to improve without the treatment proposed;
- the benefit the adult is expected to obtain from the treatment proposed outweighs the risk or harm to her;
- a less restrictive or less intrusive treatment would be as beneficial as the treatment proposed.

Appeals To A Review Board

The adult, her representative or any other interested person may request a review of:

- the determination by the Capacity and Needs Review that the adult is not capable of making a health care decision; and/or
- the selection of the TSDM; and/or
- the basis of the TSDMs health care decisions on the adult's behalf (e.g., the TSDMs knowledge of expressed or pre-expressed wishes).

QUESTIONS:

Are there any circumstances where the pre-expressed wishes of the adult may be overruled?

Should the hearing of appeals be a function of an expanded and revised Mental Health Review Board, or should a new Health Care Review Board be created?

NON-EMERGENCY SITUATIONS/MINOR HEALTH CARE

In a non-emergency situation where the adult requires minor health care, the health care provider will seek the adult's informed consent (as described in Non-Emergency Situations/ Major Health Care above) to the examination or treatment proposed.

If the adult voluntarily agrees to the proposed treatment and demonstrates to the health care provider — in her own words or manner — that she understands:

- the information being given by the health care provider,
- that the information is being applied to her situation, and
- the specific consequences of accepting or declining the health care treatment,

the health care provider will administer that treatment. If the adult declines treatment, her decision will be respected.

If the adult demonstrates an understanding of the information provided and indicates her willingness to proceed with the treatment, the health care provider will administer that treatment. If the adult declines treatment, her decision will be respected.

If the adult's response causes the health care provider to question her capacity to make the decision and if the adult does not have a representative or court-appointed decision maker, the health care provider will go to the statutory list to find a temporary substitute decision maker to make the minor health care decision on the adult's behalf.

There will be no Capacity and Needs Review for minor health care decisions.

EMERGENCY SITUATIONS

There are some emergency medical situations which are so critical that treatment must be started immediately by the health care provider without the consent of the adult — for example, in the case of a motor vehicle accident where an adult is severely injured and unable to communicate with medical personnel at the scene, or where treatment to alleviate pain is necessary to make the adult more comfortable while the health care provider seeks consent for the overall health care situation.

However, in many other emergency situations, the health care provider will have time to communicate with the adult. In these cases, the health care provider will seek the adult's informed consent (as described in Non-Emergency Situations/Major Health Care above) before undertaking an examination or initiating any form of treatment.

Where the adult's response indicates, in the health care provider's opinion, that she has the information necessary and the capacity to make an informed decision, the health care provider will abide by her decision.

Where the adult's response leads the health care provider to question her capacity to make an informed decision, and if time permits, the health care provider will seek assistance to communicate with her. This assistance may be provided by any person(s) accompanying the adult and immediately available to assist, or the health care provider will attempt to determine

if the adult has a representative who can be contacted for instruction.

If no assistance is readily available, the health care provider will seek, if possible, a second opinion as to the adult's capacity to make an informed decision regarding the pending examination or treatment.

After all reasonable efforts have been made to obtain consent from the adult or her representative, and this consent is not forthcoming, then the health care provider may conduct an examination and/or provide treatment for the adult.

[NOTE: If time and circumstances did not permit a search for a representative prior to emergency treatment, that search will be conducted after treatment or during the administration of treatment if further treatment is necessary.]

CHANGING SITUATIONS

Where an emergency condition has been resolved or has been reclassified as a non-emergency condition, continued treatment will require informed consent (as described in Non-Emergency Situations/Major Health Care above).

Similarly, a non-emergency situation could become an emergency situation at any time if there are unforeseen changes in the adult's condition. In these cases the process set out for obtaining consent in Emergency Situations (described above) will be applied.

CHAPTER 6
CAPACITY AND NEEDS REVIEW

SUMMARY

When an adult is determined to be incapable of making his own decisions, it generally means that he must relinquish his rights and decision making powers to another person. For this reason, we believe that a formal assessment of an adult's capability must only be undertaken in response to a clearly defined need, and only after all other formal or informal means of support and assistance are exhausted.

Throughout this discussion paper, we propose a variety of measures to support, assist and protect adults which do not involve determining an adult's capacity to make his own decisions. When these measures work well, the adult's capacity should not be an issue. However, in cases where the adult has no Representation Agreement or support network in place, or where the Agreement or support network has broken down, a formal assessment of the adult's needs and his capacity to make decisions may be necessary.

As a result of this occasional need for a determination of capacity, and to supplement other forms of support or assistance, we propose that:

1. A review mechanism be established to provide a formal method for reviewing the capacity of an adult and his need for assistance in making decisions, called a Capacity and Needs Review.
2. This Capacity and Needs Review function either confirm the adult's capability to make his own decisions, or serve as a preliminary step to providing the adult with decision making assistance.
3. For a review, the general definition of capacity should be whether the adult understands the nature and the consequences of decisions relating to his:
   - finances;
   - health care and treatment; or
   - activities of daily living (personal care).
4. This standard of capacity be set out as the general legal standard in legislation, and that guidelines and standards for each area of decision making - basic or complex financial management and transactions, health care and treatment, and activities of daily living - be developed in consultation with consumers, community groups and professionals and be described in the Act's regulations.
5. A Capacity and Needs Review be conducted in one of four situations:
   - during consent to major health care, if the adult's ability to give informed consent has been brought into question (see Chapter Five);

- in situations where abuse, neglect or self-neglect is suspected, and the adult's ability to make decisions about his finances, health care or activities of daily living have been brought into question, and the adult has refused services (see Chapter Four);
- when the adult has chosen a Capacity and Needs Review as the triggering event for a Representation Agreement (see Chapter Three); or
- as part of the preparation required for an application to the court to appoint a court-ordered decision maker or Guardian (see Chapter Eight).

We also propose, because a Capacity and Needs Review is different from any review mechanism currently in place, that training and certification programs for professionals be established as part of the implementation of this Review model.

In addition, we recognize that our ability to define and assess an adult's capacity to make decisions remains limited despite recent advances. We do not know, for sure, how much weight to give to thinking, understanding and social competence, and we recognize that we must continue to develop our understanding of capacity and now it relates to the ways in which people communicate. We will need ongoing research and evaluation to improve and refine the principles and procedures outlined here for Capacity and Needs Reviews.

PRINCIPLES

The following principles will form the basis of every Capacity and Needs Review:

- all adults shall be presumed to be capable of making their own decisions;
- capacity cannot be determined in the abstract, but must be considered in relation to an adult's ability to do something;
- capacity may depend on the type of decision required - an adult may not be capable of making decisions in one area, while retaining capability in other areas;
- capacity can be affected by the availability of support and resources - the lack of support and resources should not be a determining factor in the referral and review of capacity;
- an adult's capability to make decisions may be affected by changes in his environment, diet, health, medication or social support, and may improve with the passage of time, treatment or training and experience with a particular type of situation; and
- an adult retains his fundamental rights at all times during a Capacity and Needs Review.

In addition, demonstrated need only must trigger a Capacity and Needs Review, and all Capacity and Needs Reviews must take into consideration that an adult's capacity is influenced by his environment as well as his skills. For example, the adult may not appear to be capable of managing his own finances, but he may live in an environment where, with the support of family or friends, there is minimal need for him to manage money. In such a case, there is no need to determine whether or not the adult is capable of managing his own finances.

CAPACITY AND NEEDS REVIEW TEAM

Membership on a Capacity and Needs Review Team will depend on the decision making area the Team has been asked to review.

We anticipate that health care reviews would include physicians and medical practitioners. Other areas of decision making might draw a variety of people with demonstrated expertise, including medical practitioners, psychologists, rehabilitation workers, nutritionists, occupational therapists, social workers, nurses, other health care professionals, or non-professionals.

[NOTE: We also anticipate that, in most cases, a physician will provide a prognosis of the adult's condition, to help determine the length of time that decision making assistance may be required.]

Because some people are more comfortable working with particular groups, such as seniors, people with head injuries or mental handicaps, the people chosen to participate on a Capacity and Needs Review will vary according to the needs and circumstances of the adult. All members of a Capacity and Needs Review Team must be experienced in Capacity and Needs Review techniques.

To avoid potential conflicts of interest, whenever possible no member of the Review Team will be directly involved in carrying out health care treatment on - or actively managing the affairs of the adult whose capacity is being reviewed.

FAMILY, FRIENDS AND ADVOCATES

The adult's family, friends and advocate are vital in the Capacity and Needs Review process, both as supports for the adult during the Review and as essential sources of information for the Review Team about how the adult copes with decision making.

The Review Team may end up with an incorrect opinion of the adult's capabilities if the adult is fearful or distrustful, or if the process has not been adequately explained to him. To avoid this, the adult will be asked who he wants present when the Team is working with the adult. If the adult decides that he does not want the family member, friend or advocate there, or if that person is alleged to be the abuser in an abuse or neglect situation, the Team will use that person only as a source of background information.

QUESTIONS:

Should a Capacity and Needs Review Team include professionals only? Should non-professionals play a role? Are there any other functions for the family in a Capacity and Needs Review?

WHEN DO CAPACITY AND NEEDS REVIEWS OCCUR?

Except for a few cases (such as where the adult selected a Capacity and Needs Review as a triggering event) the Review is intended to be used only when other resources have failed. A

need for assessment only arises where there is an indication that the adult is unable to make a decision and the formal or informal support system has broken down.

Capacity and Needs Reviews will not occur where the adult has a well supported system or where the adult's capacity has not been questioned. Reviews will not occur unless there is a need (potential or actual) for a decision to be made. The Reviews also will not occur if the adult has a representation agreement in operation that handles the type of decision under consideration.

CAPACITY AND NEEDS REVIEW PROCESS

Once the Capacity and Needs Review Team has been selected, the Team will first determine whether there is an existing need for a decision to be made by the adult. The Team will gather all relevant information on the adult's circumstances and need for assistance in decision making from the adult and his family, friends, and advocate.

Capacity and Needs Reviews will be flexible and tailored to the individual adult. Whenever possible and practical, all or part of the Review should be conducted in the adult's own environment to obtain as reliable an indication as possible of the adult's strengths and needs.

Each Review will focus on the adult's capability to make decisions in the specific area of concern. For example, if the concern revolves around the adult's ability to handle his finances, the Review will focus on financial management, and will not consider the adult's ability to make decisions about health care or activities of daily living unless other information suggests that there is a need for assistance in those areas as well.

Finances

A Capacity and Needs Review specifically initiated to determine an adult's capacity to make financial decisions will determine whether the adult understands the nature and consequences of decisions relating to his finances or property.

[NOTE: Highly complex financial matters may require a more Specialized Team to obtain an accurate picture of both the adult's needs and capabilities.]

Health Care

A Capacity and Needs Review specifically initiated to determine whether an adult is capable of giving informed consent to a proposed health care treatment will determine whether the adult understands:

- the information being given by the health care provider;
- the specific consequences of accepting or declining the health care treatment; and
- that this information is being applied to him.

Activities of Daily Living

A Capacity and Needs Review specifically initiated to determine an adult's capacity to make decisions about his activities of daily living may determine whether the adult understands the nature and consequences of his decisions in a variety of activities. These activities may include the adult's nutrition, personal hygiene, health care, residence, work, social relations and/or safety.

QUESTION:

It is difficult to define activities of "daily living in advance of a specific problem. Should there be a more precise definition of capacity for activities of daily living? If so, what should it be?

CONTRIBUTING FACTORS

A number of factors may influence the findings of a Capacity and Needs Review on an adult's actual decision making ability, and will be taken into account in each Capacity and Needs Review.

Verbal Ability

The ability to make a decision is often inferred from a person's ability to verbally explain his decision. However, for many adults, their ability or inability to express their decision making process verbally is not a good indicator of their actual abilities.

For an adult in this group, the Capacity and Needs Review would involve a method of determining the adult's actual ability to make decisions that does not rely on his ability to verbally express his decision. This could include using a BLISS symbol board, observing the adult's behaviour, or employing a pictorial representation.

Experience

Experience or lack of experience could also affect the Review Team's perception of an adult's actual decision making ability.

The Capacity and Needs Review will take into account and, where possible, compensate for the effect of an adult's lack of experience in that specific decision making area by either:

- ensuring that the adult receives a clear explanation of the situation in a manner designed to fit his specific communicative abilities;
- providing the adult with training in decision making prior to the Capacity and Needs Review, where appropriate; or
- stopping the Review in order to allow the person an opportunity to gain experience in the specific decision making area (e.g., operating a bank account).

Medical Condition

An adult's capacity to make decisions can be affected by a health condition.

As a result, a medical practitioner will examine the adult prior to the Review to determine the effect of medical factors, such as medication, nutrition, depression, recent change in environment, blood pressure or metabolic abnormalities, on the adult's cognitive state.

The opinion of the medical practitioner may lead to a decision to delay the Capacity and Needs Review until the positive effects of remedial treatment (e.g., changes in medication or diet) have been ascertained, to a shortening of the Review period, or to a court order appointing a substitute decision maker.

THE ADULT'S RIGHTS

The adult's rights in a Capacity and Needs Review include the right to:

- know that a Review has been initiated and what form it will take;
- withhold or revoke consent to the Review at any time;
- be present and involved in all parts of the Review;
- know who will be reviewing his capacity;
- have a friend, family member or advocate present during the Review to support, translate or interpret;
- be informed, in a manner he can understand, of the result's of the review and what the results will mean to him.

CHAPTER 7
COURT-ORDERED DECISION MAKING AND GUARDIANSHIP

SUMMARY

Informal or formal support systems — such as personal support, advocacy or the provisions of a Representation Agreement — are the simplest and least intrusive methods of ensuring that an adult has the assistance she needs to make decisions.

Sometimes, however, these support mechanisms just do not exist or break down, and the adult needs the court to appoint someone else to be responsible for making decision's on her behalf.

But not every adult needs the same level of assistance or intervention for decision making, for the same amount of time. One adult might need someone to make a decision on only one issue, another might be able to resume making her own decisions within a few weeks, while still another might need a permanent decision maker to make decisions on most aspects of her life.

As a result, we propose that:

1. Legislation be introduced to create three categories of court-appointed decision maker:
   - associate decision maker, to support and assist the adult in decision making, but without the authority to actually make decisions on the adult's behalf;
   - substitute decision maker, with time-limited authority to make decisions for the adult in specific areas; and
   - Guardian, with the authority to make a wide range of decisions on the adult's behalf for an extended period of time.
2. The court process for appointing an associate/substitute decision maker or Guardian begin only after all efforts at building or re-building informal or formal support mechanisms are exhausted, based on the recommendation of a Capacity and Needs Review.

PRINCIPLES

These principles shall form part of the legislation and the court process:

- all adults shall be presumed to be capable of making their own decisions;

- every effort must be made to enable an adult to make her own decisions;
- every effort must be made to ensure that the adult receives information about the court process in a manner familiar to her;
- court orders are to be a last resort — everything possible must be done to first provide informal or formal support to the adult before an order can be made;
- all court orders under this legislation shall be the least restrictive and the least intrusive way of assisting, supporting and, if necessary, protecting the adult;
- every adult has the right to be represented by a lawyer at any point in the court process;
- decision makers appointed under the new legislation must make decisions which reflect the adult's wishes to the greatest extent possible, and which take into account the adult's ethnic, social and cultural values.

DECISION MAKERS

THE THREE LEVELS OF DECISION MAKING

Associate Decision Maker

A court-appointed associate decision maker (ADM) will support and assist the adult in decision making, but will not have the power or the authority to actually make decisions on the adult's behalf. The adult has the right to either accept or reject the ADM. The ADM may be assigned to support the adult with all decision making, or with just certain decisions.

When the adult needs to make a decision, the adult will be expected to discuss the decision with the ADM, but the ADM should also be proactive and offer advice without a formal invitation.

So long as the ADM acts honestly and diligently, he or she will not be held liable for decisions made by the adult. There may be situations, however, where the adult does not consult with the ADM or where the adult insists on a course of action with which the ADM does not agree. If the adult acts without the agreement of the ADM, the ADM will not be held liable if the adult makes an ill-advised decision.

If the ADM feels that the adult is no longer willing to work with him/her, the ADM should report this fact to the Office of the Public Guardian and Trustee (OPGT).

Substitute Decision Maker

In contrast to an ADM, a substitute decision maker (SDM) has the authority to actually make the decision(s) for the adult, according to the limits set out in the court order.

The SDM may be appointed to make decisions regarding:

- routine financial matters;

- complex financial matters;
- personal care; or
- health care.

The appointment of a SDM will be time limited.

Guardian

Where an adult's decision making ability is seriously impaired, the appointment of an ADM or a SDM may not be sufficient to give the adult the support and assistance she needs.

In these situations, a Guardian may be empowered to make a wide range of decisions for the adult — to ensure, for example, that the adult lives in the best possible circumstances, gets stimulation from visitors and from programs designed for her, and that her money is spent wisely — over an extended period of time.

The Guardian should be very involved in the adult's life, must consult with the adult to the greatest extent possible, and, when appropriate, act on the adult's expressed wishes.

RESPONSIBILITIES OF COURT-APPOINTED DECISION MAKERS

It is the responsibility of any court-appointed decision maker to encourage and enable the adult to exercise and develop her decision-making capability to the greatest extent possible.

Decision makers should be patient, involved and understanding. They should be willing to advocate, inquire on behalf of the adult and involve the adult throughout the decision-making process.

In addition, a substitute decision maker or Guardian will make decisions:

- according to the adult's pre-expressed wishes, except where to do so is impossible or is against the law; or
- when the wishes are unknown and cannot be ascertained, in a manner consistent with the adult's values, beliefs and preferences; or
- when the adult's pre-expressed wishes, values, beliefs and preferences are not known and cannot be ascertained, in the adult's best interests.

If there is a question about the adult's instructions or about how legislation and regulations affect the responsibilities of decision makers, the decision maker may seek support and advice from the OPGT. If this advice is not sufficient to clarify the concern, the decision maker may apply to court for instructions.

LIMITATIONS ON THE AUTHORITY OF DECISION MAKERS

QUESTION:

Are there some decisions that should never be made by a substitute decision maker or Guardian? Are there some decisions for which a decision maker must seek the permission of the court before making?

Examples of these kinds of decisions are voting; marriage; instituting divorce proceedings; wills; non-therapeutic surgery; signing an organ donation card; donating organs;bone marrow transplants or blood transfusions; consent to the adoption of children; withholding consent to life support; experimental or controversial treatments; and abortion.

SUPPORT AND SUPERVISION FOR DECISION MAKERS

The OPGT is responsible for educating, supporting and encouraging decision makers, and ensuring that decision makers understand the scope of their responsibilities. (Decision makers may also consult appropriate professionals for advice when needed.)

Third parties may bring their concerns about the decision maker and his or her decisions to the attention of the OPGT. The OPGT will investigate and attempt to resolve the matter through such means as mediation. If the concern cannot be resolved, the matter will be brought to the attention of the court by either the OPGT or the third party.

In addition, the OPGT will supervise all court-appointed decision makers.

Each decision maker is required to report at regular intervals to the OPGT. The OPGT will ensure that the decision maker is accountable to the adult and is making decisions consistent with the adult's wishes, values and beliefs.

COURT PROCESS

INITIATING A CAPACITY AND NEEDS REVIEW

A request for a Capacity and Needs Review — which may be made by anyone with a concern about an adult's decision-making capability — will be referred to the regional Inquiry Coordinator.

The regional Inquiry Coordinator will be specially trained and subject to clear standards of performance. The Inquiry Coordinator is responsible for making every effort to develop or re-establish formal and/or informal supports in the adult's life before a Capacity and Needs Review may be undertaken.

To initiate a Review, the Inquiry Coordinator must be satisfied that the adult:

- has one or more decisions to be made;
- has no formal or informal support to assist in making the decisions; and
- appears to be not capable of making the decisions.

If these three "triggering" conditions are present, the Inquiry Coordinator will then:

- attempt to build or rebuild formal or informal support arrangements through the offer of assistance or advocacy;
- use mediation to resolve family conflicts, if present; and
- if a family member or friend has applied to be appointed as the adult's associate/substitute decision maker or Guardian, consider and discuss the suitability of the applicant as a decision maker.

If the Inquiry Coordinator finds that any one of the three triggering conditions is not present, is successful in resolving a family conflict, or in building or rebuilding the adult's support system, the Review process leading to a court order will cease.

CONSENT TO A CAPACITY AND NEEDS REVIEW

Where the Inquiry Coordinator has not been able to resolve the adult's situation through personal support or mediation, and believes that a court-appointed decision maker is needed, the Coordinator will ask the adult if the adult will consent to a Capacity and Needs Review.

If the adult consents, the Review will begin.

If the adult withholds his consent, that decision will be respected unless the Inquiry Coordinator believes there is very strong evidence that a court-appointed decision maker is necessary. The Coordinator will then request the court to issue an order to allow the Capacity and Needs Review to proceed.

Before going to court to obtain the authority to conduct a Review, however, the Inquiry Coordinator will ask the adult's advocate and/or lawyer to assist the adult, and will then provide the adult, his advocate and/or legal representative with notice regarding the pending court hearing.

[NOTE: The adult shall be deemed to have the capacity to hire and instruct a lawyer and, if the adult cannot pay for a lawyer, the legal aid program is expected to cover these legal costs. Guidelines will be developed for lawyers who may be asked to accept instructions from apparently incapable clients.]

The Supreme Court of British Columbia will hear the application and determine, after reviewing the evidence, whether or not a Capacity and Needs Review should proceed without the consent of the adult.

REVIEW PROCESS

Once the adult has consented to the Review, or the court has ordered the Review to proceed, the Inquiry Coordinator will then be responsible for coordinating all aspects of the ensuing Review, including the establishment of a multi-disciplinary Capacity and Needs Review Team (see Chapter Six).

The Team will weigh the adult's overall ability in decision making, and will reach a decision on whether or not the adult has the capacity necessary in the areas under review.

The Team will then produce a report setting out its opinion on:

- the capacity of the adult to make the required decision(s);
- the need for the decisions to be made;
- the level of assistance the adult needs; and
- the adult's wishes, particularly with respect to the proposed associate/substitute decision maker or Guardian.

Copies of this report will be given to the adult, his advocate, the OPGT, the person applying to be a decision maker or Guardian, where applicable, and other interested parties.

The adult and his family, friends, and advocate will have the right to comment on or object to the recommendations of the Capacity and Needs Review report.

If the Capacity and Needs Review determines that the adult does indeed need assistance, but no one has applied to be an associate/substitute decision maker or Guardian, the Inquiry Coordinator will encourage the adult's family members and friends to apply. If none is willing, the Team will look to other potential applicants, including trust companies, not-for-profit societies and, as a last resort, the OPGT.

APPLICATION PROCESS

Once someone has applied to become the adult's associate/ substitute decision maker or Guardian, he or she must present a Support and Assistance Plan to the OPGT, setting out the applicant's ideas for providing support and assistance to the adult.

The Inquiry Coordinator must then give notice of the application to the adult and any other interested parties (e.g., members of the adult's family and the OPGT) to ensure that all relevant information is put before the court. The Inquiry Coordinator must also ensure that the nature of the proceeding is explained to the adult, and must offer the adult the assistance of an advocate.

The Inquiry Coordinator must make a sworn statement to the court, reporting that all other alternatives have failed. The Coordinator will also set out the way in which the explanation was given and the adult's response.

Interested parties will have the opportunity to bring their concerns about any part of the application to the attention of the OPGT. The OPGT will consider their concerns and may take steps to resolve the situation.

APPLICATION SCREENING

All applications for court-ordered decision making will be reviewed by the OPGT to determine whether:

- all relevant evidence pertaining to the adult is present in the application; and
- the level of authority being sought by the applicant is consistent with the evidence of the adult's need for decision making.

In addition, the OPGT may express an opinion about whether or not the applicant is an appropriate choice for the decision making category requested. This will be based on the recommendation of the Inquiry Coordinator.

The OPGT's report to the court will set out this information for the court's consideration, and will recommend a time period for a court review of the order.

THE ROLE OF THE COURT

The formal application for a court order will include:

- the applicant's Support and Assistance Plan;
- the report of the Capacity and Needs Review Team;
- the report of the OPGT; and
- the Inquiry Coordinator's sworn statement that notice of the application has gone to all relevant parties, and that all attempts to build or rebuild formal or informal support systems have failed.

The application may be heard by the court either in Chambers or in a full court hearing. In a full court hearing, the judge hears evidence directly from the witnesses. In a Chambers hearing, the judge reads the evidence from sworn statements.

A Chambers application will be made if:

- the adult does not dispute the application, and
- every party is in agreement with the application.

All interested parties — including the adult and her advocate — have the right to attend at either a full court or a Chambers hearing. The Inquiry Coordinator will encourage and facilitate the adult's attendance in court.

The Issues The Court Will Consider

In considering whether an order appointing a decision maker is necessary, the court must be satisfied there is evidence that:

- the adult has one or more health care, personal care, or financial decisions that need to be made;

- the adult is not capable of making these decisions without some level of support and assistance;
- the adult needs the support and assistance of an associate decision maker, a substitute decision maker or a Guardian;
- the applicant is the appropriate person to assume the role of decision maker;
- the time frame in which a court review of the adult's situation will occur.

If the court considers it necessary to appoint a decision maker, the court must determine what level of decision making the adult needs — associate, substitute, or guardianship. In each case, the court must also determine whether the decision maker's authority should be limited to certain decisions only and for a specific period of time.

Rules and procedures will be established to protect the confidentiality of information produced in these matters. For example, the court may order that a particular file will be closed to the general public, and that only the final decision will be made public.

The Court Order

Having heard all the objective and relevant evidence, comments and objections, the judge will:

- make no order if the criteria for appointing a decision maker are not satisfied;
- adjourn the hearing in order to allow the people involved to investigate alternate ways to provide support and assistance to the adult;
- appoint an associate decision maker, whom the adult voluntarily accepts;
- appoint a substitute decision maker with time-limited and issue-limited decision making powers;
- appoint a Guardian;
- appoint a monitor; and/or
- appoint an alternate decision maker who shall be empowered to make decisions in the absence of the principal decision maker (e.g., if and when the principal decision maker is on vacation, ill, etc.).

The judge will set out his or her decision in a court order. The adult and all other interested parties will receive a copy of the court order.

Selection of the Decision Maker

As is currently the case, the adult will be able to nominate a court appointed decision maker in advance. The adult will also be able to state who she does NOT want to be appointed. The court will appoint the adult's nominated decision maker unless there are valid reasons not to.

If the adult does not pre-designate a decision maker, but expresses a preference for a specific decision maker, the court will respect her wishes unless there are valid reasons to appoint another decision maker. If the adult does not express a preference, the court will appoint an able and willing decision maker who is close to the adult.

In selecting a decision maker, the court is not required to appoint the person(s) who brought the application.

The court will only appoint the Office of the Public Guardian and Trustee as decision maker when no other person or agency is able and willing to be appointed.

Appointing a Monitor

The court may appoint a monitor — who may be pre-designated by the adult — to oversee the decisions made by the decision maker on the adult's behalf.

This monitor may have access to the appropriate information on the adult's circumstances, and will ensure that the decision maker:

- is making decisions consistent with the adult's pre-expressed wishes, values and beliefs; and
- stops making decisions when the court order expires.

The monitor will alert the OPGT if he or she has any concerns about the decision maker, and will not be held liable for decisions made by the decision maker.

Registration

The appointment of an associate/substitute decision maker or Guardian shall be registered at the OPGT Registry (see Chapter Eight). If an order is changed due to a mandatory periodic review, a review requested by the adult or an appeal of the court decision, the new order shall also be registered.

Emergencies

Provisions will be made for issuing temporary court orders for decision making or guardianship in emergencies. These provisions may be used if there is a likelihood that there will be irreparable harm to the adult or to the adult's estate. The court may also issue an Intervention Order in cases involving abuse, neglect or self-neglect (see Chapter Four).

Reviewing the Court Order

Court orders may be reviewed in one of three ways:

- to ensure that the original court order is still appropriate, the order will be subject to a mandatory periodic review, according to the dates set out in the legislation (i.e., every three

years for substitute decision makers and every five years for Guardians) or imposed through the court order;

- the adult may request a review at any time, provided the request is reasonable and related to a change in the adult's circumstances; and/or
- the adult may request a new hearing, provided there is new evidence not presented in the first court hearing.

Termination

The adult or the decision maker may apply to court to terminate the original order at any time, and should notify all relevant interested parties of the application. This application may not require a court hearing. If no objection is lodged with the court within 30 days, the order will terminate automatically. If the matter is disputed, the court will hear the case and may or may not terminate the order.

Variation

Applications to increase the authority of the decision maker (e.g., where it appears that the adult now needs a substitute decision maker rather than an associate decision maker or where the adult now needs a Guardian rather than a substitute decision maker) will require a court hearing.

Applications to decrease the powers and authority of decision makers do not require a court hearing. These decisions may be delivered through a bench order. This means that the information is provided in writing to the judge, who then makes the decision on the basis of the written materials.

An application must be made to court when it is necessary to replace a decision maker. As with the original application, this modification to the order will require notice to the adult and other parties and will require screening of the new applicant by the OPGT.

Appeals

An appeal is a limited review of the original court decision, and challenges whether the first decision was rightly decided on the law and evidence.

An appeal on court-ordered decision making or guardianship will be based only on the evidence introduced at the first hearing and will be allowed within prescribed time limits.

Resealing Orders From Other Jurisdictions

Provision shall be made for the acceptance of court orders from other jurisdictions. These jurisdictions must have legislation similar to B.C.'s legislation before resealing can be considered. The legislation will set out how court orders will be acknowledged, examined and reconfirmed without the need for a hearing, unless a hearing is requested.

Court Costs, Compensation and Reimbursement

In most cases, the costs of the court hearing will be paid entirely out of the adult's estate. If the adult's estate cannot carry the cost of the lawyer, legal aid will be expected to cover the legal expenses. In some cases, however, the court may order that the costs of the application should be paid by the applicant.

The court may order that the decision maker be compensated for accepting the responsibility of decision-making. Guidelines will be drawn up to determine the appropriate amounts for compensation. In addition, the court may order that the decision maker be reimbursed for expenses incurred in performing his or her duties.

CHAPTER 8
OFFICE OF THE PUBLIC GUARDIAN AND TRUSTEE

SUMMARY

In order to support the changes in legislation and practice outlined throughout this paper, we propose that:

1. A new organization be established, called the Office of the Public Guardian and Trustee (OPGT), which will include the existing Office of the Public Trustee and its current functions, including services to children and deceased and missing persons.

2. The new OPGT provide the highest level of accountability and coordination of services to adults by combining the concepts of guardianship and trusteeship in an integrated model of service delivery. These concepts are to be reflected at the structural level with the introduction of a community Advisory Board, a single official to administer the functions of guardianship and trusteeship, and a number of service coordinators who will establish personal relationships with clients.

3. The functions of the OPGT be designed to reflect the mandate of the new legislation and that these functions include:

   - inquiry services - to provide regional Inquiry Coordinators when required;
   - Capacity and Needs Review Team contracting - to engage the services of trained professionals around the province to conduct Capacity and Needs Reviews as needed;
   - court process coordination - to review court documents; make recommendations to the court on the suitability of applicants applying as substitute/associate decision makers or Guardians; and monitor time delays and costs;
   - registration, assistance and monitoring - to operate 24-hour registries of representatives and court-appointed decision makers; educate and advise representatives and court-appointed decision makers; set standards for reporting and remuneration for representatives and court-appointed decision makers; investigate complaints about court-appointed decision makers and representatives; monitor the actions of court-appointed decision makers and representatives (when specified in a Representation Agreement); and mediate disputes between adults and their representatives or court-appointed decision makers;
   - service coordination - tc act as a representative at the request of an adult, or as a court-appointed associate/substitute decision maker or Guardian on behalf of an adult who has no family members or friends willing or able to take on the role;

- public information and education - to provide plain language information on all aspects of the guardianship model outlined in this discussion paper in conjunction with community-based agencies and associations; and
- research and evaluation - to assemble data from all components in the system for research, evaluation and periodic assessment.

4. The new OPGT be held publicly accountable through a public Advisory Board, regional Consumer Advisory Committees and a yearly public audit to be performed by the Office of the Auditor General and the Office of the Ombudsman.

In addition, we propose that the new OPGT may delegate any or all of its functions to community agencies. The OPGT will **not have a role in the delivery of assistance and advocacy** services other than to ensure that an advocate is available to an adult at five designated points in the system (see Chapter Two).

The performance of the OPGT will be formally evaluated after a period of two years.

SERVICE COORDINATION

The authority and obligations of the OPGT in assisted decision-making — either as a representative (see Chapter Three), a temporary substitute decision maker (see Chapter Five), a court-appointed associate/substitute decision maker or Guardian (see Chapter Seven) — will be the same as those of any private person similarly appointed.

Each adult requiring assistance from the OPGT will be assigned a **service coordinator**. The service coordinator will spend time with the adult to ascertain the adult's wishes, and will be assisted by specialists on such matters as daily living, health care, finances, legal issues or property transactions, depending on the area of assistance required by the adult.

Where the decision making includes both personal and financial matters, the personal needs and wishes of the adult will be paramount. The Support and Assistance Plan advanced during the process for a court-appointed decision maker (or developed in the case of Representation Agreements) will provide direction on day-to-day decisions. Any investment or property decisions made by the Service Coordinator will reflect the unique living circumstances and needs of the adult.

PUBLIC ACCOUNTABILITY

It is essential that the public and consumers have full confidence in the operation of the new OPGT.

To obtain and retain this confidence, the OPGT must monitor its own performance and must maintain a direction and philosophy consistent with the vision imparted by the community. The OPGT must be open and honest in all aspects of its operation, while respecting client confidentiality, and be fully accountable to independent third parties for all aspects of its operation.

For these reasons, specific accountability measures will be built into the operating structure of the OPGT:

Community Advisory Board

A community-based Advisory Board will provide public input and advice on such matters as:

- the setting of the OPGTs strategic direction, standards and major operating policies;
- the assessment of the performance of Capacity and Needs Review Teams;
- the scope of the OPGTs public education initiatives;
- the review and evaluation of system components and the setting out of modifications to standards, policies, legislation and regulations as necessary; andothe development of OPGTs operating costs and government funding requests.

To accomplish these tasks, the Board will scrutinize reports on all aspects of the operation of the OPGT, including the resolution of consumer complaints and appeals, the results of consumer satisfaction studies, internal and external audit reports, and reports on the financial performance of the Office.

The Advisory Board will be appointed by the Attorney General for a fixed term. The members will provide regional representation from consumer groups, service providers, self-advocates and the general public; no OPGT staff will be included on the Board. The Advisory Board may request that the Attorney General investigate the OPGT if its actions are in question.

Consumer Satisfaction Measures

- Regional Consumer Advisory Committees will be created to advise and advocate to the OPGT and the Advisory Board on behalf of clients receiving services.
- The OPGT will develop — and advise consumers of — appeal procedures to review and resolve complaints about any component of OPGT service. Where the complaint is not resolved, the actions of the OPGT will eventually culminate in a review by the Office of the Ombudsman.
- The OPGT will be regularly monitored on its assisted decision-making services. Each year, in a joint audit, the Office of the auditor General and the Office of the Ombudsman will select a sample of client files and will review the performance of the OPGT. In addition, consumers may request specific case reviews through the Office of the Ombudsman, as is currently the practice.
- The OPGT will appoint an Investment Advisory Board to oversee the investment of client funds. The Board will offer investment advice and scrutinize the performance of the OPGT.

Public Audit and Review

The OPGT will be audited annually by the Office of the Auditor General to ensure "value for money" of services provided.

In addition, the OPGT will submit an Annual Report to the Attorney General. This Report will include Consumer Satisfaction Measures as well as the Auditor General's report on the OPGTs financial performance. The Annual Report will be a public document.

FUNDING THE OFFICE

The OPGT will operate on a not-for-profit basis.

The Office will charge for trustee services consistent with private individuals performing these duties. Where an adult is unable to afford the charges, the OPGT will waive the fees. Revenue from fees, along with funding from government, will be retained by the OPGT in their entirety to fund the components of service delivery.

The OPGT will submit an annual funding request to government. The funding request will fully substantiate need within the components of the system for which the funds are requested. Subsequent accountability reports will satisfy any anticipated government concerns over effectiveness and efficiency within the guardianship system.

RESEARCH AND EVALUATION

Research and evaluation is essential to ensure that the concepts and services outlined in this discussion paper continue to evolve.

The OPGT will collect a wide variety of research data on each of the components of this guardianship model. Internal OPGT researchers will work with external researchers to continually monitor service quality and make improvements to the guardianship system in consultation with the community.

In addition, a formal evaluation of the OPGTs performance will be conducted following two years of operation. This evaluation will measure consumer satisfaction and public confidence and, where problems are identified, changes to the structure of the Office and/or the legislation will be recommended to the Attorney General. After this initial review, both the legislation and the performance of the Office will be re-evaluated every five years.

This discussion paper was formatted by the B.C. Health Association in preparation for its printing and distribution.